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Twin registers in Europe: an overview

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This paper is the first in a series that aims to give an overview of existing twin registers worldwide. A short description of 16 registries in nine European countries is presented. These registries have access to over 350 000 twin pairs and are a major resource for genetic-epidemiological research.

Keywords: genetic epidemiology, twins, multiples, databases

This paper gives an overview of European twin registers. Taken together, these registers give access to more than 350 000 twin pairs of all ages. They are a major resource for genetic-epidemiological studies of a wide range of phenotypes. Table 1 gives a concise summary of the European twin registers. Appendices 1–16 provide more detailed information on the individual registries and registers.

Table 1 European twin registers

Twin registers titles by country	No. twin pairs
Belgium	
1 East Flanders Prospective Twin Survey (EFPTS)	5000
Germany	
2 German Observational Study On Adult Twins (GOSAT)	1450
3 Munich GOLD Project (Genetic Oriented Longitudinal study of differential Development)	250
4 Berlin Twin Register	65,000
The Netherlands	
5 Netherlands Twin Register (NTR)	20,000
Scandinavia	
6 Finnish Twin Cohort Study	48,000
7 The National Institute of Public Health Twin Panel (NIPH Twins)	4000
8 The Norwegian Twin Register	40,000
9 The Swedish Twin Registry	70,000
10 The Danish Twin Register	62,000
United Kingdom	
11 Twins Plus Register	15,000
12 St Thomas' Adult UK Twin Registry	8100
13 Institute of Psychiatry Volunteer Twin Register	5000
14 Child Twin Register	1300
Italy	
15 Registry of Italian Twin Athletes (RITA)	5000
16 Twin Epidemiological Registry of Rome (TERRY)	15,500

The large population-based twin registers in Scandinavia are well known, but large population-based or volunteer twin registers now also exist in Germany, Belgium, the UK, Italy and The Netherlands.

Some registers lack large numbers of participating twin pairs, but have other unique features. The Munich GOLD Project, for example, includes longitudinal data over a 60-year period for 90 twin pairs who were first tested in 1937; in Italy a large register of twin athletes has been established; in The Netherlands the NTR has collected longitudinal data of 10 000 twin pairs from birth; the EFPTS in Belgium has collected data on placentation on a substantial number of twin pairs in the register and St Thomas' registry relies mainly on clinical investigations such as X-rays and MRI scans.

Evidence of genetic influences on disease, behaviour and other traits can be obtained from the classical twin design in which the resemblance of genetically identical, monozygotic, twins is compared to the resemblance of fraternal, or dizygotic, twins. For some rare diseases a genetic component of disease vulnerability can only be established if sufficient numbers of mono- and dizygotic twins can be studied where at least one member of a pair is affected. For such projects, the value of large twin registers is becoming increasingly clear.

Some rare conditions even need affected twins to be pooled from several registers. For example, a current study of cleft lip is collecting data on twins with cleft lip from eight registers (Mitchell, personal communication).

Most registers have assembled data from questionnaires directed at large numbers of twin pairs. The availability of phenotypic data on large numbers of dizygotic twin pairs offers the possibility of phenotypic screening to ascertain extreme concordant and discordant scoring sibling pairs, who are very informative for linkage analysis of quantitative traits. Compared with ordinary siblings, dizygotic twins have the advantage of being the same age and are less likely to have different fathers, a potential problem in other sibling studies.¹

Findings of significant heritability in one population may not be extrapolated from a second population in which there are differences in exposure to the relevant environmental factors. Replication of twin studies in different countries provides one way to study such interactions between genes and environment. Unfortunately, twin registers from southern European countries are currently under represented.

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Appendix 1

Name of register	East Flanders Prospective Twin Survey (EFPTS) ^{2, 3}
Country	Belgium
Birth cohorts	July 1964 onwards
How are twins ascertained?	At birth, prospectively and population based the EFPTS records all multiples born in East Flanders
Opposite sex twins included?	yes
Number of twin pairs in each age range	Since the start of the register, around 120 twin pairs per year. Since 1985 there has been an increase in the twin pregnancy rate and in 1996 the EFPTS recorded about 260 pairs. as of September 1997 there were 5000 twin pairs and more than 150 higher order multiple births.
Primary interests/ variables measured	Zygosity, placentation (moment of splitting in MZ), congenital anomalies and prenatal factors, cardio-vascular and physical fitness measurements, cognitive development (IQ), Child Behaviour Check List, lateralisation
Institution	Center for Human Genetics, KULeuven
Contact	Prof. R. Vlietinck, Dr C. Derom, Prof. R. Derom
Address	Gasthuisberg O&N, Herestraat 49 B-3000 Leuven, Belgium
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Appendix 2

Name of register	German Observational Study On Adult Twins (GOSAT) ^{4, 5}
Country	Germany
Birth cohorts	1915–1977 (adult twins) 1978–1996 (twin children)
How are twins ascertained?	via newspapers, magazines, twin clubs and twin meetings
Opposite sex twins included?	yes
Number of twin pairs in each age range	approximately 1000 adult twins and approximately 450 young twins
Primary interests/ variables measured	all adult twins: self-report personality and temperament questionnaires; 2 peer reports per twin on most of these questionnaires. sub-sample of 300 MZ and same sex DZ twin pairs: behaviour observations in quasi-natural situations (videos), psychometric intelligence data, mental speed data from elementary cognitive tasks, objective temperamental measures, unobtrusive behaviour registrations during an assessment day. twin children: –parental reports on temperament and personality scales
Institution	University of Bielefeld, Department of Differential Psychology
Contact	Alois Angleitner, Rainer Riemann, Frank M. Spinath
Address	PO Box 100131, 33501 Bielefeld, Germany
Tel.	49 521 1064456
Fax	49 521 1066422
E-mail	fspin@post.uni-bielefeld.de

Appendix 3

Name of register	Munich GOLD Project (Genetic Oriented Longitudinal study of differential Development) ^{6, 7}
Country	Germany
Birth cohorts	approximately 1912–1932
How are twins ascertained?	newspapers advertisements
Opposite sex twins included?	no
Number of twin pairs in each age range	about 250 identical and fraternal pairs in old age
Primary interests/variables measured	personality, intelligence, social behaviour, motivation, emotion, morality. For 35 twin pairs longitudinal data for 50–60 years are available (former Gottschaldt study, started in 1937)
Institution	Max Planck Institute for Psychological Research
Contact	Prof. Dr Franz E Weinert/Dr Ulrich Geppert
Address	P.O. Box 440109, D-80750 Munich, Germany
Tel.	49 89 38602 220
Fax	49 89 342473
E-mail	geppert@mpipf-muenchen.mpg.de
URL/website	www.mpipf-muenchen.mpg.de/BCD/PROJECTS/gold_e.htm

Appendix 4

Name of register	Berlin Twin Register ^{8, 9}
Country	(East-) Germany
Birth cohorts	1920–1999
How are twins ascertained?	based on birth registers
Opposite sex twins included?	yes
Number of twin pairs in each age range	about 60–70,000 total
Primary interests/variables measured	cardiovascular phenotypes, personality, coping
Institution	Franz-Volhard-Klinik/Max-Delbrueck-Center for Molecular Medicine
Contact	Andreas Busjahn
Address	Franz-Volhard-Klinik/MDC Wiltbergstr. 50, 13125 Berlin, Germany
Tel.	49 30 94172 277
Fax	49 30 94172 335
E-mail	busjahn@fvk-berlin.de
URL/website	http://www.fvk-berlin.de/fvkweb/nephrology/index.html

Appendix 5

Name of register	Netherlands Twin Register (NTR) ^{10, 11}
Country	The Netherlands
Birth cohorts	1986–1998 (young twins) 1940–1985 (adolescent and adult twins)
How are twins ascertained?	via commercial organisation (young twins) population registers (adolescent and adult twins)
Opposite sex twins included?	yes
Number of twin pairs in each age range	between 1000 and 1500 pairs for each 1986–97 cohort 3500 adolescent and adult pairs (participating) 3000 adolescent and adult pairs (registered)
Primary interests/variables measured	cardiovascular risk, including behavioural factors, development of psychopathology in children and adults, brain function and structure, cognition
Institution	NTR, Vrije Universiteit
Contact person	Dorret Boomsma
Address	De Boelelaan 1111, 1081 HV Amsterdam, The Netherlands
Tel.	31 20 4448789
Fax	31 20 4448832
E-mail	ntr@psy.vu.nl
URL/website	http://www/psy.vu.nl/ntr

Appendix 6

Name of register	Finnish Twin Cohort Study ^{12, 13}
Country	Finland
Birth cohorts	before, 1958, like-sex, with both twins alive in 1967 (old) 1938–1957, opposite sex 1958–1986, all multiple births
How are twins ascertained?	population registers
Opposite sex twins included?	yes
Number of twin pairs in each age range	17000 pairs old cohort 8000 pairs older opposite sex pairs 23000 multiple birth sets 58–86
Primary interests/variables measured	chronic disease risk (cardiovascular, cancer, asthma and other respiratory disease, sleep disorders and other neurological, psychopathology) health-related behaviours, particularly in adolescence
Institution	Department of Public Health
Contact	Jaakko Kaprio
Address	P.O. Box 41, FIN 00014 University of Helsinki, Finland
Tel.	358 9 191 27 595
Fax	358 9 191 27 600
E-mail	Jaakko.Kaprio@Helsinki.fi
URL/website	http://kate.pc.helsinki.fi/twin/twinhome.html

Appendix 7

Name of register	The National Institute of Public Health Twin Panel (NIPH Twins) ^{14, 15}
Country	Norway
Birth cohorts	1967–1974 (questionnaire in 1992, will be recontacted in 1998) 1974–1979 (will be contacted via questionnaire in 1998)
How are twins ascertained?	population records from Medical Birth Registry
Opposite sex twins included?	yes
Number of twin pairs in each age range	approximately 640 pairs born each year for birth cohorts from 1967 to end 1974. Questionnaire data is collected from 5864 twins (2570 complete pairs). Sample will be expanded to include birth cohorts from 1975 to end 1979.
Primary interests/ variables measured	sex differences in health and development, body mass, asthma, psychological health variables, physical health history, exercise, smoking, alcohol use, psychological well-being, pre- and peri-natal influences on adult health.
Institution	The National Institute of Public Health, Oslo, Norway
Contact	Jennifer Harris
Address	Department of Population Health Sciences, Section of Epidemiology, Post Box 4404 Torshov, N-0403 Oslo, Norway
Tel.	47 22 04 23 05
Fax	47 22 04 23 51
E-mail	harris@online.no

Appendix 8

Name of register	The Norwegian Twin Register ¹⁶
Country	Norway
Birth cohorts	1895–1944
How are twins ascertained?	population registry (Norwegian Statistical Bureau)
Opposite sex twins included?	yes
Number of twin pairs in each age range	between 800 and 900 pairs for each cohort
Primary interests/variables measured	mental illness, especially schizophrenia, manic depressive disorder and senile dementia
Institution	Department of Psychiatry, University of Oslo
Contact	Professor Einar Kringlen
Address	Box 85 Vinderen, 0319 Oslo, Norway
Tel.	47 22 14 65 90
Fax	47 22 14 29 11
E-mail	einar.kringlen@psykiatri.uio.no

Appendix 9

Name of register	The Swedish Twin Registry ^{17, 18}	
Country	Sweden	
Birth cohorts	1886–1925 (old cohort) 1926–1967 (middle cohort) 1968–1990 (young twins)	
How are twins ascertained?	old cohort middle cohort young twins	manual extraction from church records from birth records computerised compilation from The Medical Birth Registry
Opposite sex twins included?	yes	
Number of twin pairs in each age range	old cohort 11 000 (questionnaires on 3 occasions) middle cohort 37 500 (1 questionnaire to all like-sexed) young twins 22 000 (birth registration information only) some subsamples have participated in numerous questionnaires and/or in person testing data collection	
Primary interests/variables measured	aging, dementia, cognition, personality, depression, cardiovascular diseases, cancer, asthma and allergies, behavioural disorders, health and health-related behaviours, gender differences	
Institution	Institute of Environmental Medicine, Karolinska Institute	
Contact	Nancy Pedersen, Paul Lichtenstein	
Address	Box 210, S171 77 Stockholm, Sweden	
Tel.	46 8 728 7418	
Fax	46 8 30 45 71	
E-mail	nancy.pedersen@mm.ki.se, paul.lichtenstein@mm.ki.se	

Appendix 10

Name of register	The Danish Twin Register ^{19, 20}	
Country	Denmark	
Birth cohorts	1870–1992	1930–52 in the process of being ascertained
How are twins ascertained?	1870–1930	parish registers
	1930–1982	Danish Civil Registration System
	1983–1992	Medical Birth Register
Opposite sex twins included?	yes	
Number of twin pairs in each age range	1870–1930	14 000 pairs
	1930–1952	15 000 pairs (anticipated)
	1953–1982	20 000 pairs
	1983–1992	13 000 pairs
Primary interests/variables measured	mortality, life span, causes of death, aging, cancer, diabetes, the insulin resistance syndrome and related cardiovascular risk factors, clinical studies of a variety of diseases	
Institution	Odense University Medical School	
Contact	Kirsten Ohm Kyvik, Niels V. Holm, Kaare Christensen, Axel Skytthe	
Address	The Danish Twin Register, Winsloewparken 15, 5000 Odense C, Denmark	
Tel.	45 65 57 30 47	
Fax	45 65 90 65 31	
E-mail	k-kyvik@win-chs.ou.dk	

Appendix 11

Name of register	Twins Plus Register ^{21, 22}
Country	England and Wales
Birth cohorts	1994, 1995, 1996
How are twins ascertained?	birth records
Opposite sex twins included?	yes
Number of twin pairs in each age range	approximately 5000/cohort (total around 15 000)
Primary interests/variables measured	language and cognitive development, behaviour
Institution	Institute of Psychiatry
Contact	Bonny Oliver
Address	113 Denmark Hill, London SE5 8AF, UK
Tel.	44 171 740 5122
Fax	44 171 919 3866
E-mail	spjwbro@op.bpmf.ac.uk

Appendix 12

Name of register	St Thomas' Adult UK Twin Registry ^{23, 24}
Country	UK
Birth cohorts	1922–1979
How are twins ascertained?	media
Opposite sex twins included?	not currently
Number of twin pairs in each age range	> 70 yrs: 200 pairs; 60–70: 1000; 50–60: 1800; 40–50: 2000; 30–40: 1600; 18–30: 1500
Primary interests/variables measured	common diseases of aging; osteoporosis, arthritis, cardiovascular disease, asthma, blindness, dementia, backpain, skin diseases, immune function assessed by detailed clinical examination and investigation and blood phenotype
Institution	Twin Research Unit, Guy's and St Thomas' Hospital Trust
Contact	Tim Spector
Address	Lambeth Palace Rd, London SE1 7EH, UK
Tel.	44 171 928 9292x2084
Fax	44 171 922 8234
E-mail	c.manzi@umds.ac.uk
URL/website	http://www.umds.ac.uk/twin-unit

Appendix 13

Name of register	Institute of Psychiatry Volunteer Twin Register ^{25, 26}
Country	UK
Birth cohorts	no
How are twins ascertained?	via media recruitment (without reference to specific studies/diseases)
Opposite sex twins included?	yes
Number of twin pairs in each age range	5000 adult twin pairs age range 16–90+, mean age 34 years
Primary interests/variables measured	psychopathology, personality and behavioural aspects of illness, cognitive function and aging, risk factors for physical diseases
Institution	Institute of Psychiatry
Contact	Alison Macdonald
Address	Department of Psychological Medicine De Crespigny Park, London SE5 8AF, UK
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Fax	44 171 701 9044
E-mail	spjuamm@op.bpmf.ac.uk

Appendix 14

Name of register	Child Twin Register ^{27, 28}
Country	UK
Birth cohorts	from 1975 onwards
How are twins ascertained?	volunteers
Opposite sex twins included?	yes
Number of twin pairs in each age range	born before 1975: 76 born in 1975–1979: 286 1980–1984: 309 1985–1989: 433 after 1989: 195
Primary interests/variables measured	personality, behaviour problems, psychopathology, social and emotional development
Institution	Centre for Research into Psychological Development, Dept of Psychology, University of Southampton
Contact	Prof. Jim Stevenson
Address	Dept of Psychology, University of Southampton, Highfield, Southampton SO17 1BJ, UK
Tel.	44 1703 592583
Fax	44 1703 594719
E-mail	jsteven@psy.soton.ac.uk
URL/website	http://www.soton.ac.uk/~psyweb/staffpages/jsteven/jsteven.html

Appendix 15

Name of register	Registry of Italian Twin Athletes (RITA) ^{29, 30}
Country	Italy
How are twins ascertained?	from registries of the national sports federation
Opposite sex twins included?	yes
Number of twin pairs in each age range	MM = 2600 FF = 1500 MF = 900
Primary interests/variables measured	influence of genetic and environmental factors on high level sport performance
Institution	Human Biology and Twin Research Center, ISEF, and Dept of Public Health, University of Tor Vergata, Rome
Contact	Prof. Paolo Parisi
Address	Piazza Lauro De Bosis 15, 00194 Rome, Italy
Tel.	39 6 32650767
Fax	39 6 36095562
E-mail	parisi@tovrm.it

Appendix 16

Name of register	Twin Epidemiological Registry of Rome (TERRY)
Country	Italy
Birth cohorts	1901–1994
How are twins ascertained?	from official records of the resident population
Opposite sex twins included?	yes
Number of twin pairs in each age range	2100 pairs born 1901–1944 7300 pairs born 1945–1969 6100 pairs born 1970–1994
Primary interests/variables measured	life style (physical activity, nutrition, habits, etc.) and health, with special regard to major risk factors and the aging process
Institution	Human Biology and Twin Research Center, ISEF, and Dept of Public Health, University of Tor Vergata, Rome
Contact	Prof. Paolo Parisi
Address	Piazza Lauro De Bosis 15, 00194 Rome, Italy
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